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# The Ohio Cancer Information Service: Callers, Inquiries, and Responses

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THE CANCER INFORMATION SERVICE (CIS) is a toll-free telephone system consisting of regional offices that operate under the sponsorship of major cancer centers across the United States (1). The services are funded by the National Cancer Institute and often co-sponsored by the American Cancer Society and other organizations. About 65 percent of the nation's population are served directly by a regional CIS. The National Cancer Institute operates a CIS for areas not served by a regional CIS and as a backup for the local CIS.

The telephone has long been recognized by various counseling and crisis intervention organizations as a powerful tool for communicating with the public (2,3). The CIS employs this approach by encouraging the public to use the service for primarily informational purposes. The service provides a private, anonymous medium by which people can obtain answers to personal or general questions about cancer.

## The Ohio Cancer Information Service

The Ohio Cancer Information Service (OCIS) is the regional service for the State, which has a population of about 11 million. The OCIS is a program of the Ohio State University Comprehensive Cancer Center in Columbus. An integral part of the communications program of this university center, the OCIS uses its resources as well as those of the National Cancer Institute. Oncologists, nurses, and allied professionals from clinical and community programs

serve on the OCIS advisory committee. Many of these professionals also are available for consultations with OCIS telephone operators.

The purpose of the service is to give the public rapid and easy access to up-to-date, easily understood information about cancer. An important objective of the OCIS is to reduce people's fears of cancer by providing information that helps them understand and cope with the disease. The program not only includes educational information about prevention, early detection, and the value of early intervention—with the hope of enhancing personal health behaviors—but it also provides complete and accurate updates on recent advances in cancer etiology, diagnosis, and treatment. In addition, the OCIS is a resource for local cancer programs and a contact for information about basic and clinical research in cancer. The OCIS serves as a clearinghouse for health professionals seeking information about investigational programs, basic research, educational materials and programs, and services for their patients. The objectives of the OCIS are consistent with the program goals specified by the National Cancer Institute (4).

In addition to providing telephone assistance, the OCIS mails, free-of-charge, printed materials on topics such as symptoms, early detection through self-examination, treatment for specific cancer sites, and dietary information for patients receiving cancer therapy. All publications are produced by recognized cancer organizations such as the National Cancer Institute, the American Cancer Society, and other comprehensive cancer centers.

Answers to all inquiries are taken from materials provided by the National Cancer Institute or those prepared by OCIS staff and approved by the univer-

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sity center clinicians. Information on services and programs for cancer patients and their families in their own communities is also given to callers. The OCIS maintains data on agencies and institutions in all 88 Ohio counties and assists callers in gaining access to and using these resources.

The OCIS is staffed primarily by volunteers. A small professional staff (director, communications specialist, volunteer coordinator, administrative assistant, and part-time graphics artist) supervises the volunteers, prepares the informational materials, designs promotional materials, and provides overall administration for the program. The majority of calls (about 80 percent) are answered by volunteers, who are recruited from the university and Columbus communities and are screened carefully for ability as well as reliability. Many volunteers are students in nursing, pre-medicine, and allied health professions; others are retired professionals. The "average" OCIS volunteer is a woman, has a bachelor's degree or is working toward one, and is either in the 18-21 or the 40-55 age group.

The volunteers attend a 16-hour (4 hours for 4 days) formal orientation or complete a 5-week individualized training program. The training programs are intended to provide only a basis for further learning. They include clinical presentations and readings on symptoms and diagnoses of the most common cancer sites, the primary modes of cancer therapy, cancer epidemiology, and proper access to and use of OCIS materials. Many training sessions are conducted by university faculty. In addition, volunteers also role play practice calls; they begin their OCIS participation by listening to experienced staff and volunteers take calls. The volunteer coordinator

then assesses the volunteer's preparation and ability to handle calls independently, although there are continuous supervision, evaluation, and mandatory in-service training sessions.

To assure no misunderstanding by the caller, each caller is informed that the operator is not a physician and cannot attempt to suggest what is advisable in a particular patient's case.

The availability of the OCIS is publicized almost entirely through public service donations from radio and television stations and newspapers and distribution of pamphlets in local supermarkets, health fairs, conferences, and meetings. Miscellaneous promotional approaches have been used with varying degrees of success. For example, a month-long billboard campaign was conducted during August 1980, when thousands of Ohioans visited Columbus to attend the Ohio State Fair. In addition, the American Cancer Society refers callers to the OCIS. Volunteers in all of the society's county unit offices have been provided with information on the service and encouraged to use the service by officials of the Ohio Division of the American Cancer Society. During the first year, 22 percent of all the referrals to the OCIS came from the units of the American Cancer Society.

### **Analysis of Calls to the OCIS**

A Call Record Form was designed to collect a standardized set of data for each call received by the OCIS. The form is completed by the volunteer or staff member who handles the request. The data include various descriptors of the caller, the inquiry, and the response. For example, data collected on callers include sex, type of caller (cancer patient, relative, physician, general public, and others), location of caller

(State and county), and how the caller learned about the OCIS (newspaper, television, radio, American Cancer Society, and word of mouth). The subject matter of the call is assigned 1 of 42 subject codes, ranging from causes, symptoms, and treatment categories about patient care and available community resources. If the inquiry is related to a specific neoplasm, the anatomic site is coded. Additionally, it is noted if the caller requested referral to a physician. Information about the response includes whether the response was immediate or required a return call, letter, or the mailing of printed material. The source of information used in answering the question, either by telephone or by mail, is also recorded. Finally, general items are collected for administrative use and quality control. Among these items are the telephone answerer's identification number, time of day the call was received and terminated, and day of week.

The OCIS initiated service on July 16, 1979. By July 1980, 3,174 calls had been received. The number of calls per month ranged from 155 in December 1979 to 335 in April 1980. A large number of calls (303) was received in January 1980, following a major publicity effort. The calls were evenly distributed over the 5-day week of the service.

The types of callers are shown by sex in table 1. Although a significant proportion of callers (78 percent) were women ( $P < .001$ ), there was no statistical difference between sexes in the distribution of types of callers. Overall, about 33 percent of all calls were from relatives or friends of cancer patients; only 13 percent were from patients themselves. These percentages parallel the national CIS experience (4).

The content of the inquiries varied according to types of callers. Table 2 shows the numbers of calls about selected subjects according to types of callers. The pattern formed by these data complies with

Table 1. Telephone calls to the Ohio Cancer Information Service, July 1979–July 1980, by type and sex of callers

Type of caller	Men		Women	
	Number	Percent	Number	Percent
Cancer patient	85	12.1	359	14.6
Relative or friend of patient	219	31.1	844	34.4
General public	258	36.6	762	31.0
Student	28	4.0	102	4.2
Physician, other professional	72	10.2	251	10.2
Other and unknown	43	6.1	139	5.7
Total	705	....	2,457	....

NOTE: Total number of calls received was 3,174, but sex was not coded for 12 callers.

what might be expected. For example, of the calls about the causes of cancer, only 12 percent were from patients, relatives, or friends, whereas 68 percent were from the general public ( $P < .001$ ). As anticipated, patients and the people closely involved with them were more interested in treatment (80 percent of the calls in that category,  $P < .001$ ) and community resources (50 percent of these calls,  $P < .005$ ). By contrast, the general public made proportionately more inquiries about symptoms (63 percent) and diagnostic techniques (57 percent).

When the cancer site of interest was classified by type of caller, another interesting pattern emerged. Data for the six sites most commonly mentioned by the callers are shown in table 3. More calls regarding breast cancer (31 percent), compared with other sites, came directly from patients ( $P < .01$ ). For the remaining sites, only 10 to 16 percent of the calls were from patients. On the other hand, only 26 percent of the calls about breast cancer were from relatives or friends, while 48 to 72 percent of the calls about neoplasms came from this group ( $P < .005$ ). This dif-

Table 2. Subjects of telephone calls to Ohio Cancer Information Service, July 1979–July 1980, by type of caller

Type of caller	Causes		Community resources		Screening, diagnosis		Symptoms		Treatment	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Cancer patient	12	4.7	36	14.9	31	14.8	38	10.8	138	22.3
Relative or friend of patient	19	7.4	83	34.3	36	17.2	65	18.5	351	56.7
General public	175	68.1	48	19.8	119	56.9	221	62.8	52	8.4
Student	21	8.2	8	3.3	1	0.5	2	0.6	16	2.6
Physician, other professional	23	8.9	57	23.6	11	5.3	0	0.0	37	6.0
Other and unknown	7	2.7	10	4.1	11	5.3	26	7.4	25	4.0
Total	257	...	242	...	209	...	352	...	619	...

Table 3. Telephone calls to the Ohio Cancer Information Service, July 1979–July 1980, by type of caller and site or type of cancer of interest

Type of caller	Breast		Colon		Lung		Brain		Leukemia		Hodgkin's disease	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Cancer patient .....	119	31.1	20	16.4	26	13.5	8	12.5	7	10.6	10	16.7
Relative or friend of patient ...	99	25.8	58	47.5	113	58.5	46	71.9	40	60.6	36	60.0
General public .....	119	31.1	35	28.7	34	17.6	5	7.8	9	13.6	9	15.0
Student, professional .....	32	8.4	4	3.3	18	9.3	3	4.7	9	13.6	2	3.0
Other and unknown .....	14	3.7	5	4.1	2	1.0	2	3.1	1	1.5	3	5.0
Total .....	383	...	122	...	193	...	64	...	66	...	60	...

ference may reflect breast cancer patients' willingness or need to express themselves as well as their openness about their conditions. It also may reflect a growing general awareness about coping with the emotional impact of breast cancer resulting from recent autobiographical accounts in various media. Of the 383 calls about breast cancer, 37 (10 percent) were about diagnostic techniques, 55 (14 percent) about symptoms, and 81 (21 percent) about therapy. Only 16 (4 percent) of the calls concerned physical rehabilitation.

In general, the sites and subjects of the calls were consistent with the incidence of various neoplasms and with expected concerns in the community. The relatively large numbers of calls regarding causes, symptoms, and treatment is not surprising (table 4). Of the 619 calls about treatment, 80 callers were interested in the "best" treatment modality for a given disease. Only 19 questions concerned surgery, but 62 concerned radiation and 97 were about chemotherapy.

A large number of inquiries concerned unproved

Table 4. Telephone calls to the Ohio Cancer Information Service, July 1979–July 1980, by subjects of calls

Subject	Number	Percent
Causes .....	257	8.2
Symptoms .....	352	11.1
Diagnosis and screening .....	209	6.6
Treatment .....	619	19.6
Patient care .....	106	3.4
Community resources .....	242	7.6
Financial assistance .....	91	2.9
Statistics and survival data .....	79	2.5
Information about OCIS .....	99	3.1
General cancer information .....	454	14.3
Other .....	563	17.7
Unknown .....	103	3.2
Total .....	3,174	...

methods (73 calls) and investigational techniques (90 calls). An additional 22 questions concerned laetrile. The large number of calls about the less conventional modes of therapy suggests that people feel more comfortable obtaining such information from an anonymous source rather than from persons associated with the traditional health care delivery system. It is also possible that many of these calls were prompted by the media coverage often given to so-called breakthroughs.

As shown in table 4, 454 (14.3 percent) of all the calls were for general cancer information, rather than a specific inquiry. The "other" classification includes small numbers of calls about such diverse topics as nutrition, rehabilitation, genetics, cancer myths, and employment problems of cancer patients. Only 20 calls (0.6 percent) were received about rehabilitation, and only 60 (1.9 percent) about smoking; however, some rehabilitation-related subjects may have been classified under requests for community resource information.

The distribution of site-related calls indicates that more calls were received about common rather than rare sites, as shown in table 5 for the 1,741 (55 percent) site-specific calls. In general, this distribution reflects cancer's overall site-specific incidence pattern (5). The largest percentage of calls concerned prevalent sites such as breast, lung, and digestive system. Breast cancer accounts for about 14 percent of all cancer incidence and about 27 percent of incidence among women. Since the majority of OCIS callers were women, it is not surprising that 22 percent of the site-specific calls pertained to breast cancer. About 11 percent of the calls concerned lung cancer, which represents about 15 percent of all malignancies in both sexes combined. The percentage of calls regarding colon-rectal disease (7.5 percent) was somewhat lower than its incidence, which is about 13 percent of all cancers. Most under-

Table 5. Telephone calls to Ohio Cancer Information Service, July 1979–July 1980, by cancer sites named in inquiries

Site	Number	Percent <sup>1</sup>
<b>Digestive system:</b>		
Esophagus	22	1.3
Stomach	35	2.0
Colon	122	7.0
Rectum	9	0.5
Pancreas	35	2.0
Liver	51	2.9
Gallbladder	2	0.1
<b>Urinary system:</b>		
Bladder	36	2.1
Kidney	17	1.0
Other	3	0.2
Buccal cavity and pharynx	40	2.3
<b>Respiratory system:</b>		
Larynx	17	1.0
Lung, bronchus	194	11.1
Bone	55	3.0
Brain	64	3.7
<b>Skin:</b>		
Melanoma	32	1.8
Other	72	4.1
Thyroid	17	1.0
<b>Male genital system:</b>		
Prostate	50	2.9
Other	23	1.3
Breast	383	22.0
<b>Female genital system:</b>		
Cervix uteri	60	3.4
Corpus uteri	49	2.8
Ovaries	28	1.6
Other	15	0.9
Multiple myelomas	27	1.6
Leukemia	66	3.8
<b>Lymphoma:</b>		
Hodgkin's disease	60	3.4
Other	79	4.5

<sup>1</sup> Percentages are based on the total 1,741 calls that were site specific.

represented with respect to incidence were cancers of the prostate (2.9 percent of calls, 8.6 percent of incidence) and bladder (2.1 percent of calls, 4.6 percent of incidence). The liver was somewhat over-represented (2.9 percent of calls, 1.5 percent of incidence), but it is not known how many of these calls related to primary liver tumors. Since the liver is a common metastatic site, many of the 51 recorded calls may have actually pertained to secondary disease.

It also is important to evaluate the ways in which the OCIS is responding to caller inquiries. Although the satisfaction of the user population has not been

measured to date, several indirect indicators suggest that the questions are handled satisfactorily by the volunteers and staff.

In most instances, the caller received an immediate response—either a direct answer by telephone or assurance that appropriate printed material would be sent. It was necessary to call the person back for only 347 (11 percent) of the calls, an indication that volunteers and staff were sufficiently familiar with the response material and that proper materials were available in the OCIS office. Immediate responses were given for 1,210 (38.1 percent) calls; another 1,248 (39.7 percent) required only 1 to 3 minutes of additional time. Since the volume of calls was large, and is expected to increase, questions must be answered accurately with a minimum of research effort.

For each call, up to three sources of information used for telephone responses and up to three sources used for mail responses were coded on the Call Record Form. Of course, many calls required both types of response. Except for 60 calls referred to health professionals and 26 for which information was later obtained from the university's Health Sciences Library, all calls were handled by use of pamphlets and other materials in the OCIS office or directly by a staff member. Specifically, 407 requests were answered with source materials provided by the National Cancer Institute, and clinical fact sheets from the university's Comprehensive Cancer Center were read to callers in 165 instances. Thus, efforts to obtain a sufficient range of approved information were successful. Also, most requests (2,712) were answered by use of only 1 information source, 385 calls required 2 sources, and only 77 calls required 3.

Information was mailed to 1,333 callers—900 were sent 1 item, 370 were sent 2, and 63 were sent 3. The materials most frequently used were pamphlets from the National Cancer Institute (1,204) and the American Cancer Society (426). We believe that printed material from well-recognized sources assures high credibility of the information. If this is indeed so, information specifically related to health behavior (breast self-examination, for example) would positively influence the recipient's behavior; however, this speculation should be tested empirically by means of a survey of the OCIS user population.

The extent to which the public uses a cancer information service depends on the service's visibility in the community. Each caller was asked how he or she learned of the OCIS, and the various types of publicity were evaluated. No statistical differences between men and women were found for this variable. Overall, a significant proportion of the callers

(20.3 percent) read about the service in the newspapers, 11 percent saw a public service announcement on television, and 22 percent were referred by the American Cancer Society ( $P < .001$ ). Other callers learned of the OCIS from a friend, a health professional, or through other small-scale publicity efforts.

Similarly, the ways by which callers learned of the OCIS did not differ significantly when classified by types of callers. This finding is somewhat surprising because members of the general public may not think to call until a newspaper or television item draws their attention to the service. By contrast, patients or their relatives may actually be seeking specific information services. Coupled with the finding that the general public made less specific inquiries (for example, general causes of cancer), we can speculate that exposure to OCIS publicity encourages people to ask questions that are of interest but not of immediacy to them. Thus, at least indirectly, the service seems to be achieving its goal of increasing public awareness of a source of information about cancer.

### Conclusions

The findings about the OCIS user population and their interests parallel national CIS data and findings reported by a telephone tape service (Can-Dial) at another major cancer center (6). In all instances, the requests were relatively consistent with the incidence of various neoplasms in the population. The greatest difference in subject matter appeared in smoking-related inquiries—they were infrequent among OCIS callers. This difference in smoking inquiries may reflect basic differences in the types of services offered—Can-Dial was strictly a taped message service, whereas the OCIS responds directly to questions on a broader range of topics.

Beyond its provision of immediate and accurate answers to specific questions, it is difficult to assess the impact of the OCIS on the health behavior of callers and persons with whom they share information. Now that the service has been in operation for more than 1 year, evaluations in the form of retrospective surveys are being planned. First, it would be useful to assess how well persons are served by the community programs and institutions to which they are referred for assistance. Second, there is a need to examine the effect of the telephone and mail responses on a person's short- and long-term knowledge and behavior. Wilkinson and associates have presented some evidence that callers may already be more oriented to preventive measures than non-callers (7). Third, a demographic profile of the OCIS

users would be informative, since it has been demonstrated that socioeconomic variables are correlated positively with health behavior (8).

The analysis of calls to the OCIS must be tempered by the recognition that consumers of the service are a self-selected group and may not represent the total public. For example, Can-Dial users are reported to be younger, better educated, and more often married than a sample of noncallers (9).

However, the data obtained to date—if properly qualified—can be integrated into other cancer control and public education endeavors within the Comprehensive Cancer Center. The inquiries received by the OCIS help to highlight areas of community concern for which specific but broad-reaching programs can be designed and implemented. Although it will be some time before all the implications of this service (particularly with respect to behavior change) are known, the data describing the types of callers and inquiries form an encouraging pattern. That is, the service is used, at least partly, by persons with reasons to be interested in cancer, and the inquiries of these persons reflect legitimate and prevalent concerns about the symptoms, detection, and treatment of the disease. Our initial 13 months' experience with the OCIS reinforces the contention that an extensive service can be provided by means of a relatively inexpensive telephone network.

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